

# Enabling Participation in a Global Research Community



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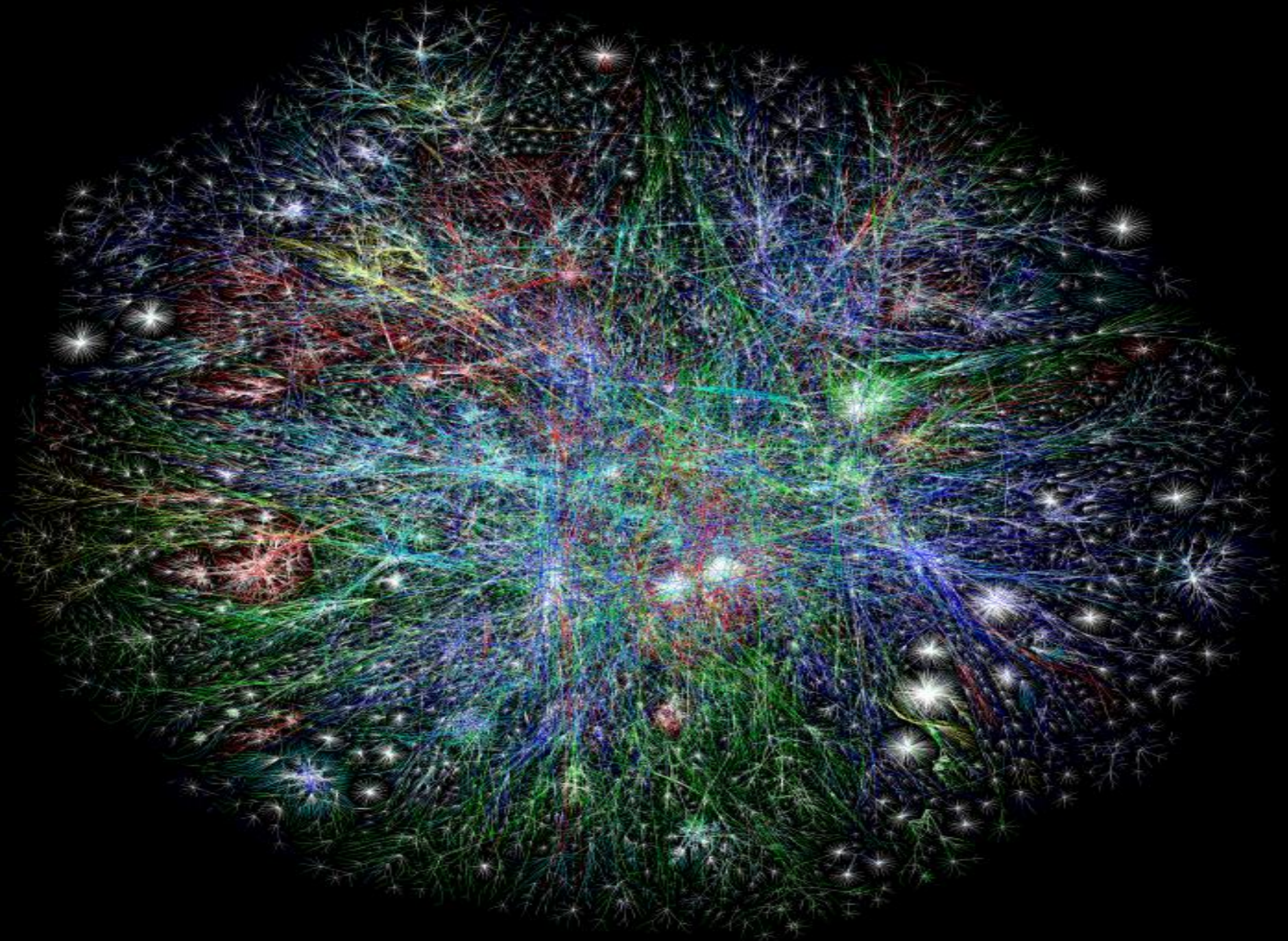


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‘subject to [certain] qualifications ... an individual’s personal autonomy makes him – should make him – master of all those facts about his own identity, such as his name, health, sexuality, ethnicity, his own image ... and also of the ‘zone of interaction’ ... between himself and others. He is the presumed owner of these aspects of his own self; his control of them can only be loosened, abrogated, if the State shows an objective justification for doing so’

*Laws LJ Wood v Commissioner of Police for the Metropolis [2009] EWCA Civ 414 at §21*











- One research project, one researcher, one jurisdiction
- Review of each new research proposal before research commences
- Paper based system of forms to navigate



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- A yellow Komatsu FL10 wheel loader is parked on a wet, reflective surface. The loader has "KOMATSU" and "FL10" visible on its side, along with a phone number "516-754-8350". The background consists of bare trees and a chain-link fence.
- Informed consent forms must stipulate all future research uses
  - Research Ethics Committees only have one opportunity to review research proposals
  - REC enforcement powers are variable
    - Few enforcement powers once research commenced
    - Authority is nationally based
    - **Decision-making is committee specific**





## **e-governance**

**Use IT as a system of governance**

**Develop a 'pathways' approach**

**'ELSI by Design'**

**Dynamic Consent interface**

**Acknowledgements for  
contributions**

**Tracking use of data to cut down on  
expert committee oversight**

# Acknowledgements

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**US Presidential Commission for the Study of  
Bioethical Issues**  
**San Francisco 2<sup>nd</sup> February 2012**





